

Πρόγραμμα Μεταπτυχιακών Σπουδών Εξειδίκευσης
Του Τμήματος Ελληνικής Φιλολογίας του Δημοκριτείου Πανεπιστημίου Θράκης
σε συνεργασία με το
ΕΚΕΦΕ Δημόκριτος – Ινστιτούτο Πληροφορικής και Επικοινωνιών
με τίτλο: «Εξειδίκευση στις Τ.Π.Ε. και Ειδική Αγωγή – Ψυχοπαιδαγωγική της ένταξης»

**«Από την ευαλωτότητα στην ψυχική ανθεκτικότητα: Παράμετροι για την
προσαρμογή των γονέων των ατόμων με νευροαναπτυξιακές
διαταραχές.»**

της
Βασιλά Ελπίδας

Μεταπτυχιακή διατριβή που υποβάλλεται
στην τριμελή επιτροπή για την απόκτηση του μεταπτυχιακού τίτλου του
Προγράμματος Μεταπτυχιακών Σπουδών Εξειδίκευσης
του Τ.Ε.Φ-Δ.Π.Θ. σε συνεργασία με το Ε.Κ.Ε.Φ.Ε. Δημόκριτος-Ινστιτούτο Πληροφορικής και
Επικοινωνιών
με τίτλο: «Εξειδίκευση στις Τ.Π.Ε. και Ειδική Αγωγή – Ψυχοπαιδαγωγική της
ένταξης»

Η τριμελής επιτροπή:

1. ΚΩΝΣΤΑΝΤΙΝΟΣ ΠΕΤΡΟΓΙΑΝΝΗΣ (Επιβλέπων)
ΚΑΘΗΓΗΤΗΣ – Ελληνικό Ανοικτό Πανεπιστήμιο
2. ΣΥΡΙΟΠΟΥΛΟΥ ΧΡΙΣΤΙΝΑ (Επιβλέπουσα)
ΚΑΘΗΓΗΤΡΙΑ – ΠΑΝΕΠΙΣΤΗΜΙΟΥ ΜΑΚΕΔΟΝΙΑΣ
3. ΜΗΤΣΙΑΚΗ ΜΑΡΙΑ (Επιβλέπουσα)
ΕΠΙΚΟΥΡΗ ΚΑΘΗΓΗΤΡΙΑ ΤΕΦ ΔΠΘ

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Περίληψη

Ο κύριος στόχος της παρούσας έρευνας ήταν ο προσδιορισμός των παραγόντων οι οποίοι έχουν οδηγήσει τους γονείς των ατόμων με νευροαναπτυξιακές διαταραχές στην ανθεκτικότητα. Πιο συγκεκριμένα εξετάστηκαν, αφενός, οι παράγοντες οι οποίοι εντείνουν τα επίπεδα άγχους των γονέων καθιστώντας τους ευάλωτους, αφετέρου, οι προστατευτικοί παράγοντες εντός και εκτός του οικογενειακού πλαισίου οι οποίοι τους έχουν οδηγήσει στην προσαρμογή και στην εμφάνιση της ανθεκτικότητας. Στην έρευνα συμμετείχαν 13 γονείς ενηλίκων ατόμων με νοητική αναπηρία ή διαταραχή αυτιστικού φάσματος. Οι γονείς συμμετείχαν σε ημιδομημένη συνέντευξη απαντώντας σε 27 ερωτήσεις. Οι ερωτήσεις αφορούσαν τόσο τους παράγοντες επικινδυνότητας, όσο και τους προστατευτικούς παράγοντες εντός του οικογενειακού πλαισίου, τους κοινωνικούς προστατευτικούς παράγοντες και τέλος την οπτική των γονέων ως προς την κατάσταση του παιδιού τους. Η ανάλυση των δεδομένων έγινε με βάση την μέθοδο της θεματικής ανάλυσης των δεδομένων, σύμφωνα με την οποία τα δεδομένα κωδικοποιήθηκαν και ακολούθησε η υπαγωγή τους στις θεματικές ενότητες οι οποίες επιλέχθηκαν με βάση τον σκοπό και τα ερευνητικά ερωτήματα της παρούσας μελέτης. Βρέθηκε ότι οι στρεσογόνοι παράγοντες ως προς το παιδί τους σχετίζονται με προβλήματα συμπεριφοράς και αυτοεξυπηρέτησης. Η έλλειψη προσωπικού χρόνου των γονέων και ποιοτικού χρόνου με τους συζύγους εντείνουν τα επίπεδα άγχους τους. Οι περισσότεροι γονείς εξέφρασαν τη δυσαρέσκειά τους ως προς την ανυπαρξία φορέων ενημέρωσης για τα δικαιώματα των παιδιών τους, την ανεπάρκεια των δομών και τις χρονοβόρες διαδικασίες των δημόσιων φορέων. Ακόμη εκφράστηκε η ύπαρξη κοινωνικού στίγματος. Ωστόσο οι περισσότεροι γονείς φαίνεται να εμφανίζουν ανθεκτικότητα γεγονός το οποίο πρέπει στους ακόλουθους προστατευτικούς παράγοντες. Εντός του οικογενειακού πλαισίου σημαντικοί παράγοντες ήταν η ύπαρξη ισχυρών συνεκτικών δεσμών και η υγιής κατανομή ρόλων μεταξύ των μελών της οικογένειας, η στήριξη των συζύγων, η χρήση «ενεργητικών στρατηγικών», η ύπαρξη οικονομικών πόρων και, τέλος, η θετική οπτική της κατάστασης εκ μέρους των γονέων. Εκτός του οικογενειακού πλαισίου καθοριστικής σημασίας παράγοντες ήταν η ψυχολογική και πρακτική στήριξη του ευρύτερου κοινωνικού κύκλου και των ειδικών.

Λέξεις – Κλειδιά

Οικογενειακή ανθεκτικότητα, προστατευτικοί παράγοντες, παράγοντες επικινδυνότητας, ευαλωτότητα, νευροαναπτυξιακές διαταραχές

Abstract

The main objective of this research survey was to identify the factors that have led people's parents with neurodevelopmental disorders to resilience. On the one hand, factors that intensify parental stress levels by making them vulnerable, on the other hand, are protective factors within and outside of the family context that have led them to adapt and to the emergence of resilience. The survey involved 13 adults' parents with intellectual disability or autism spectrum disorder. The parents participated in a semi-final interview answering 27 questions about the stressors that parents are called upon to handle, family protection factors, social protection factors, and finally the parents' view of their child's situation. The analysis of the data was based on the thematic data analysis method, according to which the data were coded and followed by their inclusion in the thematic units selected on the basis of the purpose and the research questions of the present study. It has been found that stressors towards their child are associated with behavioral and self-service problems. The lack of parents personal life and quality time with spouses intensify their stress levels. Most parents expressed their dissatisfaction because of information agencies on their children's rights, the inadequacy of structures and the lengthy procedures of public bodies. Finally, there was a social stigma. However, most parents seem to have resistance, which is due to the following protective factors. Within the family context, important factors were the existence of strong coherent links and the healthy distribution of roles among family members, support for spouses, the use of active strategies, the existence of financial resources and, finally, the positive view of the situation of parents. Apart from the family context, the psychological and practical support of the wider social circle and specialists was of key importance.

Keywords

Family resilience, protective agents, risk factors, vulnerability, neurodevelopmental disorders

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